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ABSTRACT

This guide for parents provides information on the early intervention program in New York for infants and toddlers with disabilities. It includes information on: (1) eligibility requirements for early intervention services; (2) symptoms that may indicate infants or toddlers have a disability; (3) the importance of parent participation in seeking early intervention services; (4) steps for being an effective parent advocate; (5) types of services available under the early intervention program; (6) referral of a child to the early intervention program by a parent, doctor, or other health care provider; (7) the role of the service coordinator; (8) the evaluation of infants and toddlers for early intervention services; (9) the Individualized Family Service Plan (IFSP); (10) review of the IFSP at least every six months; (11) transition of a child in the early intervention program to a preschool program with services; (12) parent and student rights, mediation, impartial hearings, and attorney fees; (13) confidentiality and student records; and (14) the history of the early intervention program. The handbook closes with a list of early intervention programs in New York State and their telephone numbers, a glossary of relevant terms, and a guide to special education abbreviations. (CR)

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ED 427 458

Your Family Rights

A Family Guide for the New York State Early Intervention Program for Infants and Toddlers with Disabilities

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NYS Department of Health
NYS Commission on Quality of Care for the Mentally Disabled

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Dear Reader:

Please take a moment to answer the questions below. The NYS Department of Health and Commission on Quality of Care value your views. Your comments will help us improve this Handbook. You may send this form to:

NYS Department of Health
Early Intervention Program
208 Corning Tower Building
Albany, NY 12237

If you wish, you may also call Connie Clarke with your comments at the Commission at (518) 473-7378.

Name, Address, Phone (optional) _____

_____

I am a ☐ parent ☐ other family member ☐ friend ☐ provider ☐ other _____

Your County: _____

Level of Education (Optional)
☐ Less than High School graduate ☐ High School graduate ☐ College graduate

Was the Handbook helpful?
☐ very helpful ☐ helpful ☐ not helpful

Was there enough information in the Handbook? ☐ not enough ☐ just right ☐ too much

Did the Handbook help you understand how to get early intervention services?
☐ very helpful ☐ helpful ☐ not helpful

Did the Handbook help you understand your child's rights?
☐ very helpful ☐ helpful ☐ not helpful

Was the wording in the Handbook easy to read?
☐ very easy to read ☐ easy to read ☐ not easy to read

Please check those sections of the Handbook that were **NOT HELPFUL** to you:

☐ Welcome to Early Intervention
☐ Referral
☐ Talking with Your Service Coordinator
☐ Evaluation
☐ IFSP Meeting
☐ Review of IFSP
☐ Transition
☐ If You Have a Problem
☐ Records and Confidentiality
☐ History
☐ Local Phone Numbers
☐ Parent's Dictionary
☐ Abbreviations

Use this space (and the back, if necessary) for any other comments or suggestions that would help us improve the Handbook:

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What Determines Eligibility?

To be eligible for early intervention services your child:

- must be under age 3
- has a developmental delay or a diagnosed physical or mental condition that has a high probability of resulting in delay in the following areas:
  - — physical development (including vision and hearing)
  - — cognitive development (thinking process)
  - — communication (understanding and expressing language)
  - — social or emotional development (relating to others)
  - — adaptive development (self-help skills)
- does not need to be a US citizen
- does not need to have a certain income
- does not need to have an address

Acknowledgement

The Family Rights booklet has been written in partnership with parents who have gone before you...parents who have also been concerned about their child's progress and well being.

For more information about the NYS Early Intervention Program or other health services available to you and your child, call any time, any day

1-800-522-5006
(Growing Up Healthy)

For information about programs for children and families, call

1-800-345-KIDS
(Decade of the Child Hotline)
or
1-800-522-4369
SATIRN II

Booklet Produced in Cooperation Between
NYS Department of Health and
NYS Commission of Quality of Care

Early Intervention

Welcome to Early Intervention

This is your book. It has been written for parents with the help of parents. As a parent, you are your child's most important teacher. Your child's life will be guided by these early years as you help your child to grow. Being a parent can be both fun and challenging. When your child has a disability or a developmental delay, life may seem more complicated than you had expected. In order to help you and your child, there are many different types of services available to your child and family under the New York State Early Intervention Program.

We hope that this booklet will help you through these times so that the dreams you have for your child may become a reality.

Should I Be Concerned?

Is one of the following true of your child:

- has difficulty sucking or swallowing?
- is too active, or not active enough?
- has health problems?
- has problems seeing or hearing?
- is not talking?
- talks differently than other children?
- is not rolling, walking or moving like other children the same age?

If you answered yes to any of these questions, you may want to think about having your child evaluated under the Early Intervention Program. You can contact your county early intervention office. A service coordinator will explain this program more fully to you. The phone number for your county Early Intervention Program is listed under the Directory of this Handbook. Your service coordinator can provide you with the names of persons or organizations that are approved to evaluate your child for free. From this list, you will be able to choose the evaluator. This evaluation will help in deciding if your child is eligible for early intervention services and what types of services may be needed. Just remember, only you can decide to have your child evaluated.

Why Parents are Important

You are your child's first and best advocate. You are the person who will help your family through the many decisions that will need to be made and the special services to be sought. You are the person who:

- knows your child
- knows what interests your child;
- knows what your child does not like;
- knows about other evaluations that professionals have written or said about your child; and
- knows what is helpful and what is not.

In a world filled with professional titles, consider yourself a FAMILY INFORMATION SPECIALIST!

Under the New York State Early Intervention Program you, the parent, are very important. If you have decided to get help for your child and family, there are six steps to follow. This booklet will help you through each of these six steps.

STEP 1 - REFERRAL OF YOUR CHILD

- you or someone else (for example, your child's doctor or other health care provider) will call the early intervention official to refer your child for early intervention services;

STEP 2 - TALKING WITH YOUR SERVICE COORDINATOR

- you will talk with your service coordinator about the Early Intervention Program;

STEP 3 - EVALUATION

- you will choose whether or not to have your child evaluated;
- you will choose who will do the evaluation and to give written permission to have your child evaluated;

STEP 4 - INDIVIDUALIZED FAMILY SERVICE PLAN

- you will decide if you want to participate in an Individualized Family Service Plan meeting;
- you and other persons on the Individualized Family Service Plan team will identify the services your child and family will receive;
- you will give your consent for any early intervention services to be provided to your child and family;

STEP 5 - REVIEW OF THE INDIVIDUALIZED FAMILY SERVICE PLAN

- you will help review your child's Individualized Family Service Plan at least every 6 months or at more frequent times if you request;

STEP 6 - TRANSITION

- you will help plan for changing services or programs when your child turns three.

Being an Effective Parent Advocate

This booklet will help you in being an effective advocate for your child. As a parent you are the most important person in your child's life. The Early Intervention Program will look to you for your advice on what your child and family needs. Below are some simple points to remember to help you be an effective advocate.

- View yourself as an equal member of the early intervention team;
- Know your family's rights; and
- Stand up for these rights.

To do that you need to:

- Be involved in every step of planning for and providing early intervention services;

- Ask questions of your service coordinator and the evaluator if anything is not clear to you;
- Ask professionals why they are recommending certain services.
- Keep copies of letters you write and notes about conversations you have with your service coordinator and service providers;
- Resolve problems early and be willing to file a complaint if you cannot find a solution with which you are happy; and
- Find out about parent support groups and advocacy groups in your area and call them early for advice, support or help.

What is the Early Intervention Program?

The Early Intervention Program is a statewide program that provides a wide variety of services to eligible infants and toddlers with disabilities, and their families. This program will help you and your family to meet the special needs of your child. You will help choose the services and the places where they will be provided depending on your child's needs. Whenever possible, these services will be provided in your home or in a community setting such as a day care center. The services that must be available to you and your child include:

Early Intervention Services

Early identification, screening and assessment services

Medical services for diagnostic and evaluation purposes

Service coordination services

Health services necessary for the child to benefit from Early Intervention

Nursing services

Family training, counseling, home visits, parent support groups

Special instruction

Speech pathology and audiology

Occupational therapy

Physical therapy

Psychological services

Nutritional services

Social work services

Vision services

Assistive technology devices and services

Transportation

In addition to these early intervention services, respite services also may be provided to you. These services can include in-home or out-of-home respite. You will have an important role in planning on how these services, if needed, will be provided. The Parents' Dictionary of this Handbook provides an explanation of these services.

If your child is found to be eligible, and you wish to have your child receive services, an Individualized Family Service Plan (IFSP) will be developed. This plan will describe the early intervention services your child will receive, and how often and where the services will be provided. When deciding on where your child will receive services, the Early Intervention Program will, when appropriate for your child, have these services provided in a natural environment. A natural environment can be your home, day care setting, or other place that normally serves children without disabilities. Remember, only the services you consent to will be provided to your child and family. You and your child have the right to receive those early intervention services included in the Individualized Family Service Plan, so make certain that this plan addresses your concerns.

Step 1: Referral

A referral means simply that you or someone else familiar with your child tells the Early Intervention Program that your child may have special needs. This is the first step for families into the Early Intervention Program. If you feel that your child needs early intervention services, you can make the referral directly. There are many others who may make referrals, including:

doctors - pediatricians, general practitioners

hospitals/neonatal intensive care units

public health nurses - Infant Health Assessment Program

early intervention programs

Early Periodic Screening Diagnosis and Treatment Program - Child Teen Health Plan

Early Childhood Direction Centers

child care centers and family day care centers

Even if some other person or organization refers your child, only you, the parent, can give permission for your child to be evaluated. If you do not want your child referred to the program, you can raise this objection with the person who is referring your child.

Sample Letter
How to Refer Your Child

_____
(Date)

Dear _____:
(Early Intervention Official)

I would like to refer my child _____ to the Early Intervention
(Name)

Program. My child is _____ and appears to have problems in his/her development. I understand
(Age)

that I will be contacted by a service coordinator who will explain the program to me and can help me choose an evaluator from a list that will be provided to me. I also understand that a Family Rights Handbook will be provided to me.

The best time to reach me is on _____, _____.
(Days) (Times)

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

Step 2: Talking with Your Service Coordinator

Once your child has been referred to the Early Intervention Program, a person known as the service coordinator will contact you. Your service coordinator will help you learn more about the Early Intervention Program. The service coordinator not only explains the program to you but also will:

- provide you with a copy of this Handbook if you do not already have a copy;
- give you a complete list of evaluators, that you can choose from. If you wish, your service coordinator can help select an evaluator;
- help arrange for the screening/evaluation, **with your permission**;
- if your child is in immediate need of early intervention services, assist you in obtaining those early intervention services by developing an Interim Individualized Family Service Plan;
- set up a meeting to plan an Individualized Family Service Plan at a place and time that makes it easy for you to attend;
- help you understand what this meeting will be like and answer questions you may have about it;
- make sure the services that are agreed on in the Individualized Family Service Plan are begun and continue as the plan calls for;
- make sure that the Individualized Family Service Plan lists other services your child and family need, if any, that are not paid for by the Early Intervention Program, **with your permission**;
- explain how your insurance coverage or Medicaid can be used and that early intervention services will be at no cost to you;
- make arrangements for the periodic review (at least every 6 months) of the Individualized Family Service Plan;
- make sure, when your child nears three years of age, that the Individualized Family Service Plan has a plan to help your child move from early intervention services to preschool or other services, if needed;

- inform you of your rights under this program and if these rights are not being met, how to resolve the problem.

If your child or family is in immediate need of services, with your permission, early intervention services may be available before an evaluation takes place. Early intervention services are sometimes needed immediately because of children's particular disabilities or complex needs, or families' circumstances, such as certain disabilities, illnesses, or other needs. In such a case, your service coordinator will work with you in developing what is called an Interim Individualized Family Service Plan. This plan will allow your child and family to receive early intervention services until an evaluation can be completed and a new Individualized Family Service Plan is written. Just remember, the evaluation and regular Individualized Family Service Plan must still be completed by 45 days.

If your child is found not to be eligible for early intervention services, your service coordinator can, if you wish, identify other services or program that may help your child and you. In addition, your service coordinator will tell you about your rights if you believe your child should have been found to be eligible. You can learn how to appeal such a decision by reading the "If You Have a Problem" part of this Handbook.

Step 3: Having your Child Evaluated

If you decide that early intervention services can help your child, the next step is to have your child evaluated. Your service coordinator will provide you with a complete list of evaluators to choose from and will help you schedule an evaluation at a time and place that is convenient for you. The evaluation and, if you are not able to provide it, transportation to and from the evaluation will be provided at no cost to you.

This is the step that will determine whether or not your child is in need of early intervention services. At this point, you will be able to request that your child be screened or evaluated. A screening can be used to see if your child has a developmental delay, or to help identify the type of evaluation that could best determine your child's eligibility and the services needed. You do not have to have your child screened. Your decision not to give permission for a screening cannot be used to keep you from having your child evaluated. You have the right to have your child evaluated even if the screening shows that your child has no delays in development.

Once you have given permission, a member of the evaluation team will tell you:

- what tests will be used;
- what information the evaluation team is looking for;
- how the evaluation team will get the information; and
- where your child will be evaluated and that you can take part in the evaluation.

In having your child evaluated, you should always remember that you play an important role in your child's evaluation. The evaluator you have selected must arrange for a multidisciplinary team to evaluate your child. This simply means that specialists from more than one area of development will be involved in your child's evaluation. The team will observe and test your child to determine if he or she is eligible for early intervention services and what types of services are needed by:

- watching your child at play, preferably in a natural setting;
- checking health and medical problems;
- talking with you about your concerns and what your child is like at home;

- reviewing developmental history; and
- giving individual tests.

The evaluation will include a physical examination of your child by a doctor or other health care provider (unless there has been a recent exam that is adequate), with your consent, a review of your child's health and medical records, a review of your child's abilities, an assessment of the special needs of your child, and an examination of the transportation needs of your child. It is together, as a part of the team, that you look at the strengths and needs of your child, and how the Early Intervention Program can help.

The multidisciplinary evaluation must be planned specifically for your child, and be sensitive to the culture and language of your child and family. If necessary, the evaluation may take place over several sessions.

In addition to this evaluation of your child, you may choose to have what is called a "Family Assessment" done by the evaluation team. This is done to help identify the concerns, resources and strengths of your family related to your child's development. This is voluntary and if you do not wish to have such a family assessment done, this cannot be used to deny early intervention services to your child.

After the evaluation is complete, you will be given a summary of the evaluation. The service coordinator will explain and help you understand the results. The evaluation summary must be, if at all possible, in the language normally used by you, such as sign language or braille. If you wish, a copy of the complete evaluation will be provided to you.

In addition, your service coordinator may, with your consent, require further tests and information. You will be provided with a written explanation for this request. Sometimes additional tests are used to better determine the level of services needed. If you feel that the evaluation is not adequate, you may make a request in writing to the early intervention official for a second evaluation. If your request is approved, this second evaluation will also be at no cost to you.

If, after the evaluation, your child is found to be eligible for early intervention services, your service coordinator will schedule an Individualized Family Service Plan meeting at a time and location that is convenient for you. If your child is found not to be eligible and you disagree, or if your request for a second evaluation is denied, you may appeal the finding by filing a request for an impartial hearing with the New York State Department of Health. If you choose to file a request for an impartial hearing, you may want to get advice from advocacy organizations before you proceed. Your service coordinator can help you locate an advocacy organization in your area.

Step 4: The Individualized Family Service Plan Meeting

The focus of the Early Intervention Program is to help your family meet the special needs of your child. The one word that is central to Individualized Family Service Plan (IFSP) is "Family". One of the reasons for developing this written plan is to help you to use skills you already have as well as help you to learn new ones to meet the needs of your child.

Family/professional partnership and working together are the keys to a family-centered Early Intervention Program. You participate in the process based upon what you feel is right for you and your child. You are an equal team member and need to share your views about your child.

What Can You Do to Prepare for an IFSP Meeting?

In order for a good IFSP to be developed, your concerns about your child's development need to be addressed. As the parent, you know your child in many ways that experts do not. Your service coordinator will help you prepare for the IFSP meeting. In preparation you may want to:

- read over the summary of your child's evaluation and ask for a copy of the complete evaluation if you think it will be helpful to you;
- read over any records you may have and bring them with you;
- talk to people who have worked with your child, such as doctors, nurses, child care staff, babysitters etc, and obtain their ideas;
- make a list of any questions you may have to bring with you;
- talk with other family members about what is most important for you and your child;
- call other parents you know, or a family support group, to make certain that you are well prepared for the meeting; and
- talk with your service coordinator about the meeting and any concerns or special needs you may have such as interpreter services.

Your Individualized Family Service Plan Meeting

If the evaluation team determines that your child is eligible for services, an Individualized Family Service Plan (IFSP) meeting will be held at a time and place that is convenient for you. The meeting will include the evaluator, early intervention official, your service coordinator and yourself, along with any other persons who you invite, such as a relative, another parent; a service provider, or advocate. Your service coordinator may wish to invite other people to the IFSP meeting, but this can happen only with your permission.

You will get a notice of this meeting from your service coordinator. In order to make certain that you and your child receive services as soon as possible, this meeting must be held no later than forty five days after the early intervention official receives a referral for your child. If you feel that this process is moving too quickly for you, or you want to think things over for a while, you can. You need to know you are the only person who can slow down the process.

When you get the notice of the IFSP meeting, make certain that the day, time and location of the meeting are convenient for you. If not, you can ask your service coordinator to make a change. Remember, you are an important member of the team and your help is needed in order to write a good IFSP for your child and family.

As a team, you will work together to write an IFSP for your child and family. In this meeting, your concerns and priorities for services are to play an important role in developing the IFSP.

What is Included in an Individualized Family Service Plan

The IFSP must be in writing and will include:

- ❑ **INFORMATION ABOUT YOUR CHILD'S CURRENT DEVELOPMENT**
  Your child's health and physical development (including sight and hearing), thinking ability, speech and language, and social or emotional development.

- ❑ **INFORMATION ABOUT YOUR FAMILY**
  What is most important to your family, your family concerns, and people or organizations that your family can rely on as needed, in helping your child's development. Additional family information is important but will be included only if families want it to be.

- **EXPECTED OUTCOMES**
  Results that your child and family are expected to reach because of the provision of early intervention services. This part will state how you, your service coordinator and service providers will decide how well the plan is working.

- **EARLY INTERVENTION SERVICES**
  This portion of the IFSP will list the specific early intervention services that your child and family are to receive. These services can be provided through what are called "Service Model Options". This simply means the way that early intervention services will be provided.

- **DATES, DURATION AND FREQUENCY OF SERVICES**
  This part of the IFSP will give information on the services including:

  - the date services will begin and how long they will be provided ("duration");
  - how often services will be provided (known as "frequency"); and
  - how much time will be spent on providing services (known as "intensity").

- **LOCATION OF SERVICES**
  This part of the IFSP will identify where your child and family will receive services. Training of day care workers and other support services, if necessary, may be included as part of the IFSP.

- **OTHER SERVICES**
  The services, other than early intervention services which your child and family may need but which are not required to be provided as part of the Early Intervention Program.

- **TRANSITION PLAN**
  The IFSP may also include a transition plan. The transition plan is simply meant to help your child and you prepare for the time when your child can no longer receive early intervention services. If your child is thought to be eligible for preschool special education services, your service coordinator will arrange, with your consent, a special meeting to discuss possible options for preschool services. This meeting will take place at least 90 days before your child can receive preschool special education services.

If your child is thought not to be eligible for these services, your service coordinator will assist you in identifying other early childhood services as part of this transition plan.

❑ **SERVICE COORDINATOR**

You may at any time during or after the meeting of the IFSP, select a service coordinator who will become responsible for coordinating the IFSP. This person may be different from the service coordinator who first worked with you, if you wish. You can choose any person from the list of approved service coordinators. It is important that you pick this person carefully since you will be working closely with this person in:

- updating your IFSP;
- organizing services that your child and family need;
- informing you about your child's and family's rights;
- finding community services;
- working with professionals;
- helping you obtain services from other programs that your child and you are eligible to receive; and
- making plans for any transitions between programs.

If you and the early intervention official agree on the IFSP, your service coordinator will give you a copy of the IFSP and help carry out the plan. If there is not agreement, your service coordinator will make certain that only those services that are agreed upon are provided to your child and family. It is important to remember that you must give your permission before services will be provided to your child and family. If you decide not to give your permission for any specific service, this choice cannot be used to keep other agreed upon services included in the IFSP from being provided to your child or family.

Step 5: The Review of Your IFSP

In order to make certain that your child's and family's needs are being met, the IFSP will be reviewed at least every six months and evaluated annually by you, your service coordinator, early intervention official and providers of services. Because the needs of young children and your family can change quickly, you also have the right to request a review of your IFSP at any time. You may have someone else, such as a family member or advocate, come with you to any of these meetings. If there were services that you had refused before, you now have the chance to decide if you would like these service provided. If there are services being provided that you do not think are needed any longer, you can decide to have these services stopped. If you want to change how often or where services are being provided, this step allows you to talk about these concerns.

To help prepare you for this review, look over your IFSP and decide if your child is making the progress that was expected. If not, think about what additional services you think are needed or if services are not being provided in a way that helps you help your child. With this information, you will be ready for your review meeting.

If at any time you and your service coordinator agree, in writing, that your child is no longer in need of services, your service coordinator will send you a notice that your child is no longer eligible for early intervention services.

Step 6: Transition

Part of your IFSP may include information on transition. This process is to help your child and family get ready for the time when your child will be too old to receive early intervention services. One of the issues that will be talked about with you is the possibility that your child may need preschool special education services. In order to help make this decision, you will be asked to give your permission to having a special meeting held to discuss these services. This meeting will be held at least 90 days before your child is eligible for preschool special education services. If your child is thought not to be eligible for preschool special education, other options for providing early childhood and other support services will be discussed with you. In all cases, the transition meeting must be held at a time and place that is convenient for you and other persons who must attend. You also must give your permission before any records such as evaluations or your IFSP are sent to any early childhood or preschool program that may serve your child.

Again, your service coordinator will help you by:

- scheduling visits for you to programs or settings;
- contacting people who may be able to provide services to your child and family;
- assisting you so that the transition is smooth and no time is lost between receiving services from the Early Intervention Program to other programs; and
- sending evaluations, assessments, IFSP and other reports to programs, with your permission.

If You Have a Problem

Sometimes parents and early intervention staff may disagree with one another. These disagreements can often be worked out by discussing them with a staff member or director of the program or by seeking help from your service coordinator. Sometimes, these efforts may not solve your problem or concern. In order to make certain that your child's rights are protected, the Early Intervention Program gives you other ways for making a complaint. You will be told about your right to file complaints throughout the process including:

- when your child has been referred to the program;
- when you give consent for your child to be evaluated;
- whenever your child is found not eligible for services;
- at your first IFSP meeting and annual review of the IFSP; and
- whenever the early intervention official wants to change the services being provided to your child and family.

If you are not able to find a solution by talking with your service coordinator or early intervention provider, you can ask for mediation, an impartial hearing, or file a system complaint. This part of the Handbook will tell you more about these options. You have the right to use these options to help you solve problems. Some examples of possible problems that these procedures can be used include disagreements about:

- an eligibility decision made by an evaluator;
- what services your child and family should receive under the IFSP;
- how often or where these services will be provided; or
- the failure of the early intervention official or service coordinator to take timely actions, as required by the State.

What Is Mediation

One of the ways that you can try to resolve your concerns is through mediation. Mediation is a way for the parent and the early intervention official (or someone who represents that person) to meet with a mediator who is trained to help people come to an agreement. The mediation meeting is meant to be as relaxed and informal as possible. The mediator treats each person the same way

and helps them work together to reach an agreement they both like. Each person gets to tell their side of the story and give ideas on how to solve the disagreement. Mediation must be provided at no cost to you. In order to make certain that your complaint is taken care of quickly, this process must be completed within 30 days after the local mediation program has received your request.

Mediation

If you decide you want to use mediation to try to solve your problem, you must write your early intervention official to make this request. After making this request, the early intervention official will notify a Community Dispute Resolution Center. A mediator from a Community Dispute Resolution Center will contact you and arrange for mediation if the early intervention official is also willing to go to mediation. The mediator will explain the mediation process to you, and help you understand your rights. This includes:

- the right to have a person of your choice go to mediation with you (this may include a friend, advocate or attorney);
- the right to have interpreter services provided, if feasible and if you need them;
- the right to stop mediation at any time and pursue your complaint through an impartial hearing;
- confidentiality of the process; and
- the right to have mediation held at a convenient place and time for you.

If you choose to have an attorney with you, you must inform the early intervention official. If the early intervention official decides to bring an attorney, you will be informed of this ahead of time.

If you and the early intervention official are able to find a solution to your complaint, the mediator will prepare a written agreement for both of you to sign. You will be provided a copy of this agreement which, if possible, will be written in the language you normally use. Once you reach an agreement, it will be the responsibility of your service coordinator to make any changes in your IFSP that are needed. This must be done within five days in order to make certain that your child and family receive the right services.

If an agreement is not reached, your service coordinator will tell you about your right to request an impartial hearing and help you in making this request if you wish.

Sample Letter - "How to Request Mediation"

_____
(Date)

Dear _____:
(Early Intervention Official)

I would like to request mediation. I am concerned about the early intervention services that my child, _____ is receiving or should be receiving.
(Name)

I hope you will agree to this request. If so, I understand that someone will contact me to make arrangements for mediation. The best time to reach me is on _____, _____.
(Days) (Times)

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

What is an Impartial Hearing?

An impartial hearing is a formal procedure conducted by a hearing officer. At the hearing, both parties will give information and may present witnesses to support their position. Parents may bring a friend, another parent, advocate, or attorney. The hearing officer will review all the evidence and will make a decision on how your complaint will be resolved.

This may mean that the hearing officer will agree with your views and provide you with what you request, or it may mean that the hearing officer will disagree with your views and not require any changes to be made. In some cases, the hearing officer may agree with you only in part and order limited changes in services. Unlike mediation, it is the hearing officer who makes the final decision. The hearing officer will be an administrative law judge or administrative officer assigned by the Department of Health, who knows about the Early Intervention Program.

Impartial Hearing

If you decide to request an impartial hearing, you should do so by writing to the Commissioner of the New York State Department of Health. Generally, you can ask for an impartial hearing at any time. However, if the complaint involves your child's eligibility, the request must be made within six months of the date that your child was determined ineligible for services. Like mediation, an impartial hearing must be held at no cost to you.

Once your request for a hearing is received, the Department of Health will send you a notice that will:

- let you know the day, time and location of the hearing which should be reasonably convenient to you;
- briefly state the issues which are the subject of the hearing, if known;
- explain how the impartial hearing will be conducted;
- tell you that you can bring any person of your choice to the hearing, which can include an advocate or attorney;
- advise you that interpreter services for the deaf will be provided, if needed;

- inform you of your right to testify, to present evidence, produce witnesses, and to question witnesses of the other party;
- let you know that if you disagree with the decision of the hearing officer, you can appeal the decision;
- inform you that your child will continue to receive services that are not in dispute until a decision is made by the hearing officer or until an appeal, if any, is concluded; and
- remind you that you can try to use mediation to resolve your problem.

If your early intervention official will be represented by an attorney, you should get a notice of this within three working days after the early intervention official received the notice of your hearing. This will give you some time to find an attorney or advocate to help you if you decide this is needed. Your service coordinator can help you find legal and advocacy services in your area that may be able to assist you.

Before the hearing takes place, there are a couple of things that you must decide and do. First, you must choose if you want to have your child attend the hearing. Also, you must decide if you want the hearing open to the public. The hearings will be closed to the public unless you request an open hearing and the hearing officer makes a determination that the hearing should be open to the public. Finally, you must provide the opposing party a listing of the evidence, including witnesses that will testify on your behalf, at least five working days before the hearing. You will receive a similar list from the other party.

The hearing officer is responsible for conducting the impartial hearing. This means that the hearing officer:

- can require you and the opposing party to attend a private conference with the hearing officer before the hearing in order to explain how the hearing will be run;
- can order the opposing parties to make an opening statement explaining their views;
- will administer oaths to any person testifying;
- will decide what evidence can be submitted or kept from being used; and

- will make certain that a record of the hearing is made.

Once the hearing has been completed, the hearing officer will make a final decision on how to resolve your complaint. However, any time before this decision is sent to you, you have the right to reach an agreement with the opposing party. If you do this, you must inform the hearing officer so that the hearing can be stopped. Once a ruling is made, you will be provided with a copy of this written decision. This decision will include:

- the findings of the hearing officer and legal conclusions;
- a decision about how the dispute is to be resolved;
- an order requiring the decision to be implemented; and
- your right to appeal this decision to court if you disagree with the ruling.

A copy of this decision will be sent to you, your service coordinator, and the opposing party; the Commissioner of the Department of Health or a representative of the Commissioner, and any State agency affected by the decision. Your early intervention official or service coordinator will make certain that your IFSP is changed and implemented, based on this decision, within five days after getting a copy unless you or another party files a request with a court to appeal this ruling.

Attorney Fees

If you are considering getting help or advice from an attorney, you should be aware that the reasonable costs for this legal assistance may be paid for you in certain circumstances. The costs that may be paid for your attorney's assistance under the Early Intervention Program are limited to the costs for legal assistance for: (1) an impartial hearing if the county or City of New York is also represented by an attorney, and (2) a court appeal, if any, of the hearing decision. In addition, you will be reimbursed only if all the following requirements are met:

First, mediation has been completed. This standard has been met if you have made a written request for mediation and:

- you participated in mediation but were not able to reach an agreement with your early intervention official or you requested an impartial hearing; or

- the early intervention official has refused to participate in mediation; or

- the mediation proceeding has not been held within two weeks of receipt by the early intervention official of the request unless you have asked for or agreed to an extension beyond two weeks.

Second, you were able to resolve your problem by substantially prevailing at the impartial hearing or through an appeal to the courts.

"Sample Letter - How to Request an Impartial Hearing"

_____
(Date)

Commissioner of Health
NYS Department of Health
Corning Tower Building
Empire State Plaza
Albany, New York 12237

Dear _____:
(Commissioner)

I would like to request an impartial hearing for my child, _____
(Name)

regarding early intervention services. I am having a problem with _____

_____

_____

_____

The best time to reach me to arrange for a reasonably convenient time, place and date for the hearing is on _____, _____.
(Days) (Times)

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

What is a System Complaint?

In addition to the mediation and impartial hearing procedures, there is a third way to file a complaint. This process, known as a system complaint, allows you to file a complaint with the State Department of Health if you believe that your early intervention agency or service providers are not performing their work as the law requires. This may involve just your child or it may relate to several children whose rights are not being protected. Some examples may include:

- charging for evaluations;
- not paying for insurance co-payments or deductibles for early intervention services;
- providing services without parental consent;
- refusing to consider ways of having children served in a natural environment such as the home or another community setting; and
- not meeting the time requirements for evaluations or developing IFSPs.

Under this process, the State Department of Health is required to investigate your complaint. However, if the complaint is about a provider that is approved by another State agency, the State Department of Health can refer your complaint to that agency. No matter who investigates your complaint, this must be done within 60 days after your complaint is received by the Department of Health.

If you decide to file a complaint, you may do so by writing or calling the State Department of Health. After making the complaint, you will be told by the Department what procedures will be used to investigate your complaint. This may include interviewing you, and any person named in the complaint, as well as persons likely to have useful information about the complaint. In addition, a site visit to the program may be part of this investigation. You will be told how you can appeal the findings of the investigation to the U.S. Department of Education if you disagree with the results. Any information that could identify you will be kept confidential unless you approve.

Once the investigation is completed, you will receive a copy of the final report. This report will show its findings to each complaint you have made, and any corrections that must be made if the problems you complained about are found to be true. If any corrective actions are required, there will be a later review to make certain that all the corrections that were required have been made.

Sample Letter - "How to Make a System Complaint"

_____
(Date)

Commissioner of Health
NYS Department of Health
Corning Tower Building
Empire State Plaza
Albany, New York 12237

Dear _____:
(Commissioner)

I would like to file a complaint because I believe that _____
(Name and address)

_____ is/are not performing their work as the law requires. I would like the Department to investigate the following actions: _____
(Statement of Charges)

_____. I understand that my complaint will be investigated within sixty days and that I may be interviewed and will receive a copy of the final report.

The best time to reach me is on _____ (Days), _____ (Times).

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

Your Child's Records and Confidentiality

There are several protections provided for the confidentiality of personal information. In order to make certain that information is accurate, you have the right to review and inspect your child's records being kept by an Early Intervention Program. This includes:

- being able to obtain a copy of the record;
- having information in the record explained to you if you wish; and
- having a person who represents you review the records.

If you want, you can ask your service coordinator for help in getting the records you want to see. The service provider, service coordinator, evaluator or early intervention official must let you review the records within ten days after they have received your request. But if your request is being made to help you get ready for your IFSP meeting or for mediation or an impartial hearing, you should get a response in five days.

If you want to look at these records, you cannot be charged for any costs for finding them. However, if you want a copy made, you may be charged a fee. This fee cannot be above 25 cents per page. You should check with the program what the total cost for copying will be before having the records copied for you.

After reviewing the records kept on your child and family, you have the right to request that changes be made if you believe the information is not accurate, misleading, or violates the privacy or other rights of your child and family. If you want any corrections made, you can make that request to the early intervention official, service coordinator, evaluator or the service provider. Your service coordinator must help you in making this request if you need help. Once you have made a request for changes to your child's record, the early intervention official, service coordinator, evaluator or service provider has ten days in which to respond. This will result in your being told that:

- the records have been changed as you requested; or
- the records have not been changed.

If the records are not changed as you asked, your service coordinator will tell you that you can have a statement placed in the record regarding your views, and that you can request an administrative hearing by the county or City of New York. This administrative hearing will be conducted by a person who has no direct interest in the outcome of the hearing.

There are other basic requirements to make certain that personal information about your child and family are kept confidential. Early intervention officials and all providers of early intervention services are required to protect confidential information about your family. In order for information to be released, your early intervention official may ask you to sign a general release which will allow information to be shared with programs that will be serving your child. If you sign a general release, you can change your decision at any time.

If you do not want to sign a general release, you can instead sign a selective release. This type of release will indicate the persons who can obtain confidential information and from whom they can obtain it.

Finally, there may come a time when the information being kept is no longer needed. Your early intervention official will tell you if this is the case. In order for any personal information to be removed from your child's record, the early intervention official must get your approval. A complete record or a record limited to your child and family's name, address, and types and dates of early intervention services received may be maintained by the municipality. This limited information will be kept confidential.

Sample Letter - "How to Ask to Review Your Child's Records"

_____
(Date)

Dear _____:
(Early Intervention Official/Service Provider/
Service Coordinator/Evaluator)

I would like to review the records of my child, _____ who is receiving early
(Name)

intervention services from _____ .
(Names of Service Providers)

I understand that if I have any questions that I can have information in the record explained to me, and have someone I select review the records for me.

The best time to reach me is on _____, _____.
(Days) (Times)

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

Sample Letter - "How to Ask for a Change in Your Child's Record"

_____
(Date)

Dear _____:
(Early Intervention Official/Service Provider/
Service Coordinator/Evaluator)

I would like to request a change in the records of my child, _____.
(Name)

The change I wish to have made is as follows: _____

_____
(Statement of change)

I understand that you will respond to my request within 10 days. If you decide not to make this change, I understand that I have the right to have the following statement added to the record:

" _____
(Statement of your views about the record)

_____."

The best time to reach me is on _____, _____.
(Days) (Times)

Sincerely,

_____
(Name)

_____
(Street)

_____
(City/County)

_____
(Phone)

History of Early Intervention

In 1975, US Congress passed the Education for all Handicapped Children Act which states that all school age children, including those with disabilities, are guaranteed a free and appropriate public education. This law is commonly referred to as Public Law 94-142 (PL 94-142).

In 1986, US Congress passed an amendment to this law, which:

- gave the same rights to pre-school aged children between three and five years of age (commonly referred to as the Part B program);
- gave states the choice of setting up a comprehensive, statewide program for infants and toddlers with disabilities, under three years of age, and their families, called the Early Intervention Program. (Commonly referred to as the Part H program.)

When Part H was enacted, Congress determined that early intervention must focus on the whole family in order to work. The Part H Early Intervention Program was established "to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and their families." The federal law requires the Governor of each state to choose an agency to lead in the development of this program and coordinate services and policies among the several agencies which provide services to infants and toddlers and their families. In New York, the State Department of Health has been selected by the Governor to administer the Early Intervention Program. In order to implement this program, a law was enacted in New York in 1992 to allow the Early Intervention Program to be established.

Local Numbers for the Early Intervention Programs

County	Telephone	County	Telephone
Albany	518-447-4683	Niagara	716-284-3254
Allegany	716-268-9458	Oneida	315-798-5249
Broome	607-778-2851	Onondaga	315-435-3230
Cattaraugus	716-373-8050	Ontario	716-396-4358
Cayuga	315-253-1301	Orange	914-294-7961 X1365
Chautauqua	716-753-4799	Orleans	716-589-7004
Chemung	607-737-2028	Oswego	315-349-3510
Chenango	607-337-1660	Otsego	607-547-6474
Clinton	518-565-4798	Putnam	914-225-3641 X275
Columbia	518-828-3358	Rensselaer	518-270-2654
Cortland	607-753-5028	Rockland	914-364-2623
Delaware	607-746-3166	St. Lawrence	315-265-3730
Dutchess	914-431-1620	Saratoga	518-584-7460
Erie	716-858-8944	Schenectady	518-386-2815
Essex	518-873-6301 X361	Schoharie	518-295-8705
Franklin	518-483-6767	Schuyler	607-535-2704
Fulton	518-762-0720	Seneca	315-539-9294
Genesee	716-344-8506 X557	Steuben	607-776-9631 X2146
Greene	518-943-5201	Suffolk	516-853-3130
Hamilton	518-648-6141	Sullivan	914-292-0100
Herkimer	315-866-7122 X12	Tioga	607-687-0623
Jefferson	315-785-3283	Tompkins	607-274-6600
Lewis	315-376-5428	Ulster	914-339-7792
Livingston	716-243-7290	Warren	518-761-6415
Madison	315-366-2298	Washington	518-746-2400
Monroe	716-274-6858	Wayne	315-946-5749
Montgomery	518-853-3323	Westchester	914-593-3100
Nassau	516-535-3440	Wyoming	716-786-8854
New York City	212-226-0434	Yates	315-536-5160

A Parent's Dictionary

Advocacy - the act of supporting or defending a child's interests and rights.

Assessment - procedures used to identify a child's needs, the type of services that a child and family will receive, and the family's concerns and priorities about their child's development.

Assistive Technology Devices and Services - equipment and services that are used to improve or maintain the abilities of a child to function including such activities as playing, communicating or eating.

At Risk - a term used for children who may, in the future, have problems with their development that may affect learning or development.

Audiology - identification of children with hearing impairments and provision of services for hearing loss and prevention of hearing loss.

Cognitive - a term that describes the process used for remembering, reasoning, understanding, and making decisions.

Confidentiality - the right that personal information about a child and family is not released without parent consent or only when permitted or required by law.

Consent - the approval a parent gives to a program or the county, generally in writing. Consent is always voluntary and a parent may revoke it at any time.

Counseling - advice or help given by someone qualified to give such advice or help (such as a psychologist or social worker).

Developmental - having to do with the steps or stages in the growth of a child.

Developmental Delay - an indication that a child has not attained the expected level of development based on the child's age.

Developmental History - the developmental progress of a child in such skills as sitting, walking, or talking.

Developmental Tests - tests that measure a child's development compared to the development of other children at that age.

Disability - an indication that a child has a developmental delay or has a physical or mental condition which is very likely to result in a child having a developmental delay.

Due Process - procedures designed to protect a person's rights. This includes requirements for confidentiality, consent and complaint mechanisms.

Dominant Language - the language or other mode of communication that the family normally uses.

Early Intervention Official - the person that the county or New York City has appointed to be responsible for early intervention services provided to eligible children.

Early Intervention Services - services designed to evaluate and serve children with disabilities under 3 years of age and their families. These services are provided with parent consent and to the maximum extent possible in a natural environment.

Eligibility Requirements - the requirements a child must meet to be able to receive early intervention services. This will include the age of the child and whether or not the child has a disability or developmental delay.

Evaluation - a process used to determine if a child meets the eligibility standards for early intervention.

Family Training - services provided by qualified personnel to assist the family in understanding the special needs of the child and in promoting the child's development.

Health Services - health-related services necessary to enable a child to benefit from other early intervention services.

Home Visits - visit in your home by a professional for the purpose of planning and providing early intervention services.

Impartial Hearing - a formal process at which a family's complaints can be heard by a hearing officer who will resolve the dispute or complaint regarding the child's evaluation, IFSP or certain other issues.

IEP - Individualized Education Plan. A plan for a child's special educational services that the parent and a Committee on Preschool Special Education (for

children 3-5) or that the parent and a Committee on Special Education (for children 5-21) will develop if their child qualifies for these services.

IFSP - Individualized Family Service Plan. A written plan for the child's and family's services in the Early Intervention Program that the parent, an evaluator, service coordinator and early intervention official will develop together.

Interim IFSP - when the child and/or family are in apparent immediate need of early intervention services, a temporary IFSP can be developed to allow the child and family to receive early intervention services after the child has been referred to the program and before an evaluation is completed.

Lead Agency - the state agency that the Governor has chosen to oversee and coordinate early intervention services. The Department of Health is the lead agency for Early Intervention in New York State.

Mediation - a method for solving a problem that uses persons trained in helping people resolve their own problems. In mediation, it will be up to the parent and the early intervention official to try to reach an agreement with which both are satisfied.

Natural Environment - a setting that will allow a child to receive services where other children without disabilities are typically served. This may include home or a day care setting.

Nutritional Services - services that help address the nutritional needs of children which include identifying feeding skills, feeding problems, food habits and food preferences.

Nursing Services - assessment of health status of the child for the purpose of providing nursing care, and provision of nursing care to prevent health problems, restore and improve functioning, and promote optimal health and development. This may include administering medications, treatments, and other procedures prescribed by a licensed physician.

Occupational Therapy - services that relate to self-help skills, adaptive behavior and play, and sensory, motor and postural development.

Outcomes - statements of changes that parents want to see in their child or family. These statements are part of the IFSP.

Parent - a parent or person in parental relationship to a child or an appointed surrogate parent.

Parent Support Group - discussion and information sharing meetings for parents of children with disabilities.

Pendency - a due process right that the parent and child have that allows the child and family to continue to receive certain early intervention services while the parent works to resolve a dispute.

Personally Identifiable Information - includes family names, social security numbers, addresses, and other information that could be used to identify the family.

Physical Therapy - services to prevent or lessen movement difficulties and related functional problems.

Placement - the place where services will be provided to the child, which if possible should be in a natural setting such as the home or day care.

Psychological Services - administering and interpreting psychological tests and information about a child's behavior and child and family conditions related to learning, mental health and development.

Respite - temporary child care that may be available to families of children with disabilities. This may include care provided in the home or at another place.

Screening - Instruments and observations used to assess the child's developmental status and to indicate whether a child may be eligible or what type of evaluation is warranted.

Service Coordinator - someone who acts as a coordinator of an infant's or toddler's services and works in partnership with the family and providers of early intervention services. This person is to help the family obtain necessary services, and arrange periodic meetings to review the child's progress.

Service Model Options - the ways that early intervention services may be provided to a child and family such as:

- Individual home and community based visits which allow for one-to-one visits to a child and family at home or in another natural setting;
- Facility-based individual visits which allow for services to be

provided at the site of an early intervention program on a one-to-one basis to a child or family;

- Parent-child groups which allow for a group of parents and children to receive services at either the site of an early intervention program or a community setting, such as day care;
- Group developmental interventions which allow for services to be provided on a group basis to children and family members either at a community site or an early intervention program; and
- Family support groups which allow for support services and training to be provided to parents, siblings and other family members to promote the development of a child.

Social Work Services - preparing an assessment of the social and emotional strengths and needs of a child and family, and providing individual or group services such as counseling or family training.

Special Instruction - includes designing of learning environments and activities that promote the child's development, providing families with information, skills and support to enhance the child's development.

Special Needs - (as in a child with "special needs") - a term used to describe a child who has a disability or developmental delay, and requires special services or treatment.

Speech Pathology - services for children with delays in communication skills or oral pharyngeal disorders.

Surrogate Parent - a person who is appointed to act in place of the parent when parents are not available to participate in making decisions about their child's involvement in the Early Intervention Program. A parent may voluntarily designate a surrogate parent.

Transition - the process where the child will move from the early intervention program to other programs such as pre-school special education at age 3.

Transportation - providing or reimbursing the cost of travel necessary to enable a child and family to receive early intervention services.

Vision Services - evaluation and assessment of vision functioning and visual training.

A Parent's Guide to Abbreviations

ADA - Americans with Disabilities Act

AFDC - Aid to Families with Dependent Children

B/DDSO - Borough/Developmental Disabilities Services Office (in the Office of Mental Retardation and Developmental Disabilities)

BOCES - Board of Cooperative Educational Services

CAH - Care at Home

CCDBG - Child Care and Development Block Grant

CCF - Council on Children and Families

CCRR - Child Care Resource and Referral Agency

CHC - Community Health Center

COTA - Certified Occupational Therapy Assistant

CPS - Child Protective Services

CPSE - Committee on Pre-school Special Education

CSE - Committee on Special Education

C/THP (EPSDT) - Child/Teen Health Plan (Early Periodic Screening, Diagnosis and Treatment Program)

CQC - Commission on Quality of Care for the Mentally Disabled

DDPC - Developmental Disabilities Planning Council

DOH - Department of Health

DSS - Department of Social Services

D&TC - Diagnostic and Treatment Center

ECDC - Early Childhood Direction Center

EICC - Early Intervention Coordinating Council

FERPA - Family Educational Rights and Privacy Act

FFP - Federal Financial Participation

FFY - Federal Fiscal Year

FSS - Family Support Services

HCFA - Health Care Financing Administration (in the U.S. Department of Health and Human Services)

HHS - U.S. Department of Health and Human Service

HMO - Health Maintenance Organization

HR - Home Relief

IDEA - Individuals with Disabilities Education Act

IEP - Individual Education Program

IFSP - Individual Family Services Plan

IHAP - Infant/Child Health Assessment Program

IHO - Impartial Hearing Officer

IUGR - Intrauterine Growth Retardation

LBW - Low Birthweight

LEICC - Local Early Intervention Coordinating Council

LRE - Least Restrictive Environment

MAP - Medical Assistance Program ("Medicaid")

MCH - Maternal and Child Health

MOU - Memorandum of Understanding

NICU - Neonatal Intensive Care Unit

OAD - Office of Advocate for the Disabled

OASAS - Office of Alcoholism and Substance Abuse Services

OMH - Office of Mental Health

OMRDD - Office of Mental Retardation and Developmental Disabilities

OSEP - Office of Special Education Programs (in the U.S. Department of Education)

OSERS - Office of Special Education and Rehabilitative Services (in the U.S. Department of Education)

OT - Occupational Therapy

PA - Public Assistance

P&A - Protection and Advocacy Program

PCAP - Prentatal Care Assistance Program

PHCP - Physically Handicapped Children's Program

PICECP - Permanent Interagency Committee on Early Childhood Programs

PPN - Prenatal and Perinatal Networks

PPPEHP - Pre- and Post-Natal Parent Education Hospital Program

PRC - Pediatric Resource Center

PT - Physical Therapist

PTA - Physical Therapist Assistant

QA - Quality Assurance

SED - State Education Department

SNAP - Supplemental Nutrition Assistance Program

SSA - Social Security Administration

SSBG - Social Services Block Grant

SSI - Supplemental Security Income

ST - Speech Therapist

UAP - University Affiliated Program

VESID - Vocational and Educational Services for Individuals with Disabilities (in the State Education Department)

WIC - Women, Infants & Children (Supplemental Food Program)